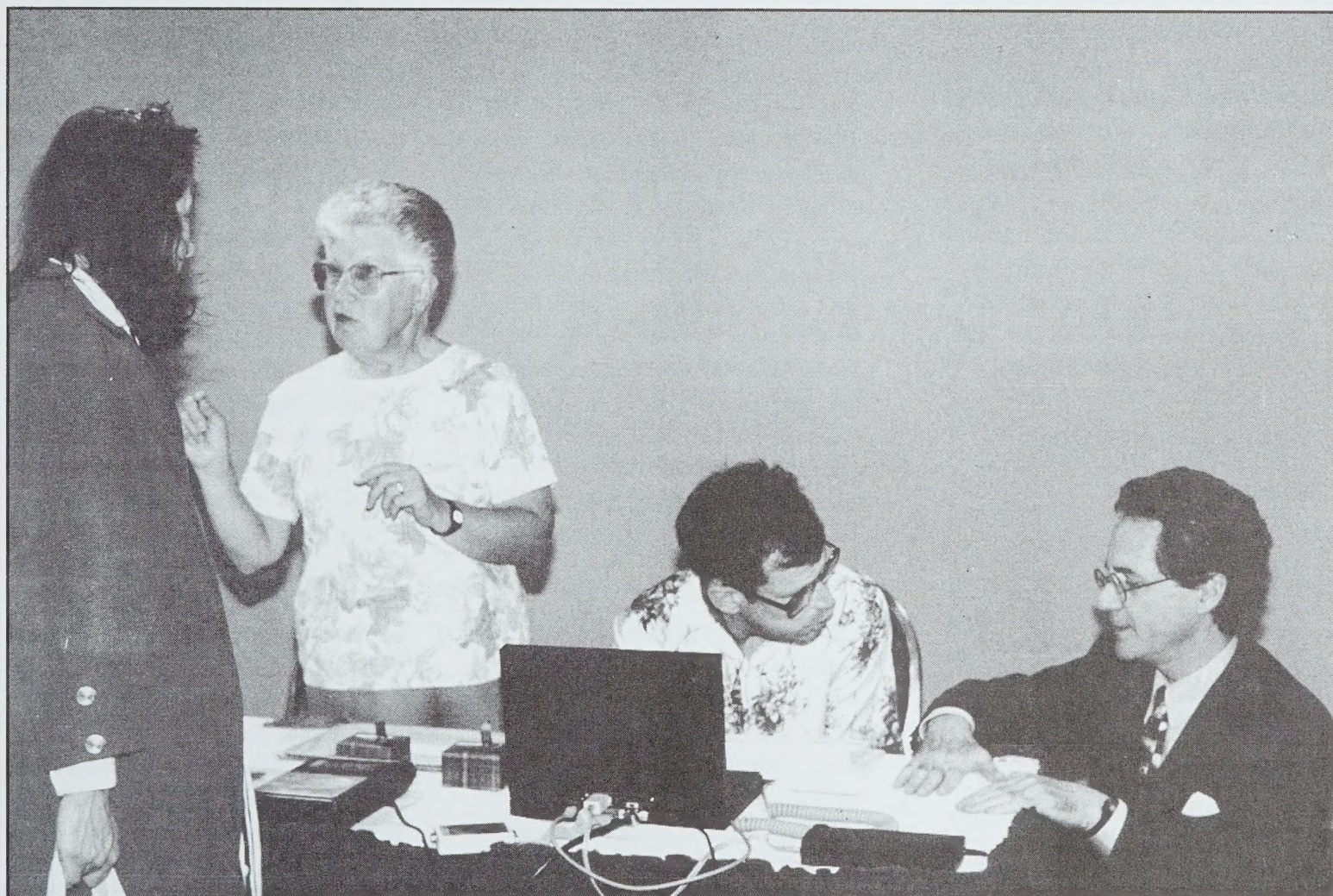


COMMUNICATING TOGETHER

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ComTog OnLine

<http://www.ahs.uwo.ca/orcn/assoc/comtog>

Real Communication

SUZANNE CLANCY &
PAUL MARSHALL



Suzanne Clancy

From Peter Lindsay & Shirley McNaughton

We are delighted to welcome and thank our guest editors for this issue, Paul Marshall and Suzanne Clancy. We hope you will agree with us in thinking they have put together a fascinating issue on a very interesting topic — real communication.

From our guest editors

Welcome to the Summer 1998 issue of **Communicating Together**. We hope you will find the theme of *real communication* as enjoyable and interesting as we did in exploring it. We have just completed another annual editors' meeting and we think we have an exciting and informative year ahead for our readers. But more about that later.

From Suzanne Clancy

Our annual planning meeting is always an exciting time for us. We review the previous year and plan the upcoming four issues. We were especially pleased to have Peter Lindsay with us and feeling more like his old self. We also extend our congratulations to Shirley McNaughton

who has completed her Ph. D. and is now, officially, Dr. McNaughton. Well done Shirley! You make us proud and you are a wonderful role model for those of us still struggling with our educational pursuits.

Publication dates

You may have noticed that of late, we have had some difficulty meeting our long-standing publishing schedule of March, June, September, and December. More often than not, the delay has been the result of very busy schedules on the part of your voluntary editors. As this issue will demonstrate, two of our editors have made major presentations in recent weeks, necessitating extensive preparation and travel time. Others of us, like everyone, are dealing with ever-increasing demands at work due to severe fiscal constraints, downsizing, and the closure of many programs for individuals in need of our support. To assuage our collective guilt over several late deadlines, Associate Editor Nola Millin suggested we publish seasonally (Summer, Fall, Winter and Spring), thus allowing for human and technological delays. Henceforth we shall. This is our first *Summer* issue.

Subscription rate changes

We also discussed the need for Sharing to Learn to increase the prices for subscribing to **Communicating Together**. This will be the first price increase since 1992. There were two major factors contributing to the need to increase subscription rates. First, we can no longer absorb the increased mailing and production costs that have been growing gradually over the years. Second, ISAAC has initiated a policy to expand its number of Affiliated Publications and this has resulted in costs that need to be shared by both ISAAC and its affiliated publishers. The agreement

with ISAAC for special rates with their affiliated publications is a 15% discount for members. The new prices shown on page 16 reflect this.

All the editors felt that any increases must be kept to a minimum for consumers, students and seniors. You will see this reflected in the new rates.

The new prices will take effect for the 1999 issues of **Communicating Together**. You will see them in the renewal notices that are mailed with the magazine in the Fall and Winter issues. The additional \$5.00 fee for **ComTog-Online** will continue.

We will be using an honour system for those who pay the special rate. We are sure our subscribers will support us by ensuring that the appropriate rate is paid.

Themes for next year

At our associate editors' meeting, we also discussed what themes would be most relevant and important to cover in next year's issue of **Communicating Together**. The themes we decided on are *Real Communication* (this issue); *Preparing for the Real World* (the Fall, 1998 issue); *Community Partnerships & Volunteer Involvement* (Winter, 1998); and *Dealing with Change* (Spring, 1999).

In *Preparing for the Real World*, we will be looking at the role of education in training AAC users for the world beyond high school. What can they expect? How will they deal with success and failure? What supports will be in place? How will they proudly deal with their individuality in a system that too often only rewards normalcy?

The theme of the winter issue will address the need for community supports and volunteer activities that are increasingly being used to supplant or replace resources lost through government cutbacks and the lack of

funding for new initiatives. In Ontario, we see pressure to become a volunteer society out of financial necessity. What are the implications of this for the quality of life of AAC users?

Spring, 1999 will be devoted to the impact of change on a person with a disability. How does a disabled person deal with change? When is change positive? Are AAC users being left behind as technology advances?

From Paul Marshall

In this issue, we are happy to share an example of what we believe was *real communication* taking place in Halifax, Nova Scotia, this June. Shirley McNaughton and I attended the 1998 Canadian Association of Statutory Human Rights Agencies (CASHRA) Conference and much new learning occurred for us both throughout the entire conference. We saw a great deal of new learning as well, on the part of those who attended our session! My presentation is reprinted as the *Feature* article in this issue. As you will see, the presentation I made is an overview of what life is like as a nonspeaking individual. Shirley's presentation at the same conference follows immediately as this issue's *SymbolTalk*. Shirley talked about Blissymbolics within the context of discussing AAC as a potential *Agent of Change*, the theme of the conference.

In *Paul's Place*, Shirley and I do some reflecting on the events that we were able to take in at the CASHRA conference. We highlight some of the many key remarks and ideas that stood out in our minds and Shirley shares her thoughts regarding *real communication*. The opportunity of sharing experiences with a group of individuals dedicated to enhancing the independence and quality of life of all sorts of vulnerable people was exhilarating indeed. We hope you will be

able to catch some of that spirit from our recollections.

Nola Millin in her treatment of real communication considers the difference between *plain* communication and *real* communication. Plain communication in her mind is communicating our needs or any necessary information. Real communication on the other hand is communicating our thoughts, feelings, and ideas beyond surface issues. She points out that having the opportunity for real communication is a critical function of being alive — it is a basic need for us all to be able to communicate our deepest emotions and thoughts with families and friends. But she also points out that real communication is particularly difficult for an AAC user to achieve. Nola, in her way, is bringing back the art of letter-writing, this time via today's high-tech-age e-mail. She reflects upon what she calls that pain-in-the-back way of writing letters by typewriter. I remember it well. I made more mistakes than you would believe because I kept hitting the wrong keys. I would not go back to those days for anything! I feel the same as Nola does — e-mail is a great blessing to anyone in the ACC community as well as in the general population, whether it be used for doing business or corresponding with friends.

Tracy Shepherd talks about the extent of the commitment required to "buy into" the use of AAC. She questions if we are willing and prepared to go the distance required, to spend the time and energy needed and to be patient enough to wait for the benefits of something we originally have to take on face value. For Tracy however it is worth it for the payoff is power — the power that comes with independence! I fully agree with Tracy. I too wonder, however, if our society is ready, prepared, and willing to deal with the fallout of this technology. There is no doubt AAC equipment can eventually level the playing field

between nonspeaking individuals and the verbal population. Tracy comments on how, with AAC, consumers are buying the power to establish and maintain their own independence. Also, in Tracy's article, we learn the vital lesson of seeing the whole person when presenting options on what to buy into.

In *Getting Technical*, Rob Haaf discusses our plans for further enhancing the features of **ComTog Online**. These new features will make it easier and more flexible for AAC users with access to the internet. He also introduces the topics he will cover in the *Getting Technical* section starting with the fall issue. We are very excited about these new developments.

Once again Alda Steprans invites and welcomes an AAC consumer to give her perspective on what it is like to have to struggle daily with communication. We, like Alda, welcome and thank Audrey McGee for her willingness to share some of her thoughts and feelings with our readers. Again Audrey points to the vital importance that *time* plays in communicating with anyone who has to use some form of AAC.

As always, Geb Verburg makes us think. He comments on what *real communication* is and cites four barriers an AAC user faces in attempting to achieve real communication. In addition to identifying the barriers however, Geb also talks about some possible ways of overcoming them. He describes a video called *Communicating Matters* made by Barbara Collier, along with a number of colleagues and friends. He points out that the video might go some way towards informing the public on how to communicate with someone who uses AAC.

We hope all our readers enjoy this "Summer" issue of **Communicating Together** — even those readers for whom it is now winter! Let's just think of it as "season #2". §

PAUL MARSHALL

Last fall I received an e-mail message from the Nova Scotia Human Rights Commission asking if I would make a presentation about AAC at their Canadian Association of Statutory Human Rights Agencies (CASHRA) Conference, to be held in Halifax from May 31st to June 2nd, 1998. I asked Shirley McNaughton to present with me. My presentation at the conference follows. Shirley's presentation follows in this issue's SymbolTalk. Our general reactions to the conference and what we learned from it are in Paul's Place.

It is quite an honour for both of us to be here, talking to you about a topic that we feel so deeply about, Augmentative and Alternative Communication. I, along with Shirley, am on the Board of Directors for Blissymbolics Communication International (BCI). I maintain BCI's website and two other web sites. I am hoping to briefly show you a couple of them at the end of our presentation. Both of us are involved in developing a computer program called *BlissInternet* which we will be talking about before our time is up. I also work as a research assistant at Bloorview MacMillan Centre one day each week in their Microcomputer Applications Program in Toronto. For you who are wondering what I am using for this presentation, I am using a normal laptop with a Dectalk multivoice unit to produce the speech.

Before we go into the body of our presentation, Shirley and I would like to introduce two very special people. We couldn't do half of what we both do without their ongoing support and love — Shirley's husband, Bob McNaughton, who it seems is always waiting in the car! My mom and also my friend, is always a source of empowerment to me. She is always there giving a lot more than she receives! It is with the support of these people that we are here.

**Talk, talk and more talk,
that is all we can hear
around us. Who are we? We
are the silent voices that live
in your cities, towns and
villages across the nation.**

Talk, talk and more talk, that is all we can hear around us. Who are we? We are the silent voices that live in your cities, towns and villages across the nation. We are the nonspeaking population who have to use some form of augmentative and alternative communication. The slides that are appearing as I talk will show you a few of us.

We are a child, a teenager, an adult, with countless dreams, hopes, wants and needs. We want to fit in and have a lifestyle with quality and meaning, just like you. We aren't asking for more but we aren't asking for less. We have no choice but to live in silence day by day. The hours will go by and not a word will come out of our mouths. Who are we? We are a son, a daughter, a brother, a sister, a parent, a grandparent. Yes, we are a member of your community.

Our society can provide for persons with all types of limitations the liberators that unlock the countless locked doors to the outside world. The main and the vital key unlocking many doors is the key of communication. Without the key of communication any person lives as a very trapped individual. This key is so much taken for granted that we often overlook it. Here is one example: I weekly go to Toronto on the bus from Hamilton, a trip that takes approximately an hour. Many times, I see and hear my fellow riders reach for their cell phones. I just shake my head because it is so far removed from the lifestyle that I was given to live. Through many locked doors we have come. Through many locked doors we need to go.

The world is still a foreign land for many of the issues we face as nonspeaking and handicapped individuals. As we go into the twenty-first century we must realize it is our future and it is our duty to set up the blueprint for a better tomorrow. Although many people will help, the leadership for mapping our future will be on our shoulders and no one else's.

Let's face it, very few people meet the norms of any society. In Canada, three out of ten Canadians have a reading problem. This greatly alters their opportunities. Health problems, employment cutbacks, abuse in families and countless other factors alter people's lives. People with "handicaps" are members of a subculture. They are viewed as not meeting social standards.

It is vital that we build a society that is ready and willing to include persons with disabilities. I would like you, for just a moment, to try to write with your non-dominant hand. This is what it is like for any person with a disability who is trying to fit in. We are always trying to fit into our communities with "non-dominant" hands while our communities are using their dominant hands.

I am sure that each of you in this room enjoys it when you get some time to do nothing in your busy life. I would like you to think what it would be like if you had a lifetime of doing nothing — *no* demands and *no* responsibilities. I am quite sure you would go crazy. (In my case I would go crazier!) As human beings, we are made to do stuff, to be active and to take part in the world around us. We all know that when we have willing hands that are not allowed to do anything, our community is the poorer for it. Persons with disabilities are often deprived of opportunities to contribute. We are so often on the receiving end of everything but hardly ever on the giving end.

A majority of nonspeaking individuals couldn't be full time workers and that includes myself. It is too hard to put in 35 hours a week at a job and still have the strength to maintain our highest level of independence. It's time for us in Canada and in other countries to really look at the many options we have for including disabled persons. We will all benefit by providing them with meaningful work. We often measure ourselves by our pay cheques, our houses, our cars and the holidays that we are able to take. We do not measure ourselves by how much we are able to give back into our communities, or by the extent to which we take up opportunities for volunteering. We especially do not value a mindset of doing things for no money

at all. There is an army of Canadians with limitations that if tapped, would create more jobs within Canada. If only we could sit back and really see the resources and unmet needs that are sitting on Canada's door step, we would create jobs like we wouldn't believe. We shouldn't look for a

One of the greatest things that society can give to anyone is to be needed and to have a feeling of usefulness in one's world.

non-productive life for persons with disabilities in a society filled with all ranges of disability. As a society, we need to ask ourselves "Are we setting the standards too low for persons with disabilities?"

How do nonspeaking individuals fit in? When society sets low goals, we are not expected to go to college or to university, to get jobs, to get married, to have families or to be owners of land or houses. The list goes on. It is easy to have a feeling of very low self-worth if one is a member of the nonspeaking subculture. Not many of us are allowed to question and be given the opportunity to grow. Without this option being given to this cultural group, it will always be an untapped resource. Is this what we need or want?

For any person to have self-worth, there is a need to have a purpose. Without this our lives become meaningless and full of self-pity. One of the greatest wrongs that society can do to persons is to prevent them from feeling needed and from having a feeling of usefulness in their world. This cultural barricade badly needs to be addressed as we move ahead into the twenty-first century.

As we are discussing different issues that affect persons who use

some form of augmentative and alternative communication, we need to remember that a speech impairment could affect anyone at any time through a sickness or an accident. Any one of us can be thrown into a life and a lifestyle of living with a disability. In my case, it is because of a lack of oxygen at birth. (I just didn't want to come out into this cold world!) From birth I was tagged with the label of cerebral palsy and forced to develop a different lifestyle if I was going to make it.

Throughout my life, I have had many blessings that helped to develop the inner person who lives within this "disabled" body. My parents and my two older brothers never viewed me as a disabled or handicapped son or brother. They didn't treat me any differently. Our parents ran a market gardening farm and my brothers and I were expected to pull our weight with the daily responsibilities of the farm duties. At an early age, my dad and my two older brothers started teaching me how to drive the tractors. In my teens, I was working the land by myself. I was included in everything within our farm lifestyle. If I couldn't do something, I was put at a job that I could do. There is no doubt in my mind, that if I hadn't grown up in a farm environment and learned how to cope with my disability, I would probably be in a wheelchair. There is no way that I would be doing the stuff that I am deeply involved in now.

When I look at human rights as they relate to persons with disabilities, especially the population of nonspeaking individuals in Canada, I reflect back on the environment with which I was so very blessed. Sit back and think. What would it be like if, when you got up tomorrow, your voice and most of your physical capabilities were gone, not for a

couple of days but gone forever. Who would you be? What would you do? You would basically be the same person after you accepted all the changes. You probably would keep some of your individual status in your work and community because you would retain some degree of ability to relate to your peer group. All of us in this room have some level of status that helps us get

along in the world. We all lead very full and productive lifestyles.

The story is quite different for most of the persons who are nonspeaking and who have all kinds of daily physical and communication limitations. Most of us sit in wheel chairs. Unlike the general population, our chances of getting a good education are poor. Few of us are totally literate. We

are the nonspeaking people across this nation. You don't hear much from us because many of our voices are silenced. We look to the dawning of a new horizon, a new vision, to be *included*, to be treated with dignity and to be given opportunities to reach our own levels of independence. No, we aren't asking for the things that can't be done in society, but for the things that can be done. §



Questions being asked after Paul and Shirley's presentation

The following thoughts were sent to us by a volunteer who works with an AAC user.

My Thoughts On The Silence

Written by a friend of an AAC user

People say of the nonverbal, "I wish they could tell us what they think."

A window of opportunity opens.

They express themselves in cumbersome communication.

People are shocked at both the depth and scope of thoughts and feelings

Finding freedom at last.

And, oops, it is not always what people wanted to hear

But the opportunity is more important than the means or the content.

Let us create and celebrate the opportunities.

by (Mrs.) Vivian C. Rowe
vrowe@npiec.on.ca

AAC as an Agent of Change

SHIRLEY McNAUGHTON



Shirley McNaughton

Following Paul's presentation at the CASHRA conference (see the Feature article), I introduced my section of the workshop with the following words:

Paul mentioned how proud he was to be here presenting with me today. I share the same feeling toward him, a hundredfold! As the first teacher of Blissymbolics, back in 1971 at the Ontario Crippled Children's Centre, I had the privilege of watching many young children, like those you have just seen in the slides, learning to communicate with Blissymbols and also growing in their language capabilities and moving into literacy. Today, I can be proud not only of my own students, but also of the students whose teachers I introduced to 'Bliss'. Paul was taught his Blissymbols by Barbara Rush, an exemplary teacher with the Hamilton School Board in Ontario. He would be the first to tell you the impact it made on his life — to be given a language that enabled him to express his thoughts, questions, concerns. We both appreciate being

able to share with you two specific agents of change with which we are very much involved —

Blissymbolics and BlissInternet.

Paul had asked me to describe briefly Blissymbols, Bliss users and the organization we were representing — Blissymbolics Communication International (BCI). I explained BCI's goal of helping Bliss users — in Ontario, throughout Canada and around the world — through the development of training materials, the offering of workshops, the holding of an annual Bliss Users' Conference and Friends of Bliss Evening, and the development and support in applying BlissInternet, a computer tool that allows Bliss users around the world to communicate with other Bliss users as well as with the rest of the world. Paul and I later demonstrated BlissInternet's capabilities including word and Bliss processing, off-line reading and preparing of messages, and automatically connecting to the Internet for message transmission. I found it interesting personally to observe that this presentation to human rights activists was a natural extension of BCI's mandate. In describing BlissInternet, we were sharing a means of interacting with and learning about persons of different language backgrounds and presenting a medium of communicating across national barriers. And we were bypassing any barriers that might arise from different levels of literacy ability.

Slides were used to support a brief history of Blissymbols, beginning with one of Charles K. Bliss, creator of Blissymbolics and author of the book *Semantography* (1965). This book, in which Mr. Bliss presents his philosophy and the

rationale for his initial symbol lexicon, is regrettably only available in a few public and personal libraries. There are, however, a number of Blissymbol resource books, published by Blissymbolics Communication International (BCI). These are available from BCI and Bridges. (For contact information, see below). Several examples of different types of Bliss boards and Bliss technology used by persons with physical and speech impairments were shown. The distinction BCI makes between Bliss *users* and Bliss *alumni* (those who once used Blissymbols but who are now fluent in using print) was explained.

I chose to introduce Blissymbols through an advocacy message. First, I presented the key symbols needed to transmit my message. To understand the composition of Blissymbols, the meaning of the elements needs to be known. There are over 100 *key symbols* which are used in different combinations to create specific meanings. I gave examples of some symbols that contribute to the *language infrastructure* of Blissymbolics. I also showed two of the many *strategies* available in the system of Blissymbolics.

For the message I wished to convey at the CASHRA '98 Conference, I needed the key symbols shown in Figure A (See page 8). The language capabilities that I chose to present within this short demonstration related to the role of *indicators* in the system of Blissymbolics. Each indicator is derived from the large form of the symbol and the meaning that this symbol represents. For example, a small (mini) version of the symbol for the past is used for the past tense indicator. The deriva-

tions for several indicators are shown in Figure B (See page 8). The strategies that I introduced were those of (a) using the *combine* symbol to form a new symbol, unique to the individual who created it and (b) the *opposite meaning* strategy, which allows the user to communicate the opposite meaning to that represented by the symbol on the display. These are illustrated in Figure C, page 9, along with an example of a combined symbol I created for the title of the conference, *Agents of Change*.

I described a banner I had seen in Guelph a week before the conference. It pertained to National Access Awareness Week and used the acronym of THERE to symbolize the areas in which access was needed. I used the *generalization* Blissymbol along with the symbols for *vehicle*, *house*, *learning*, *play* and *work* to depict Transportation, Housing, Education, Recreation and Employ-

ment — the access needs represented in the acronym THERE. (See Figure D, page 9.) I pointed out the need to add *communication* to the list and offered two (unsatisfactory to me) new acronyms! (See Figure E, page 9.)

I closed my Blissymbol demonstration by revisiting the areas needing access and stressing their importance to persons with severe speech impairments. Their needs are great, but in return, these individuals give much. The entire world can benefit from the new knowledge regarding values, ideas and insights (through the unique observations) that AAC users bring. (See Figure F, page 10.) My last Bliss illustration focused on the *cause* and *effect* symbols. The effect of AAC users serving as agents of change is a better world for all persons. The Bliss version of this message is shown in Figure G, page 10.

Following a demonstration of BlissInternet and a short visit to the BCI website <<http://home.istar.ca/~bci>>, we ended our session by playing a recording of the song, *Take the Time*, accompanied by slides of Kari Harrington as she was growing up. The words of the song are reprinted at the end of *Paul's Place*, page 23.

Reference:

Bliss, C.K. (1965).
Semantography-Blissymbolics.
Sydney, Australia: Semantography Publications.

Blissymbol Publications:

Available in Canada and USA,
from Bridges, phone 905-838-1411,
fax 905-838-1487.
For non North American enquiries,
phone BCI, 416-242-9114,
fax BCI, 416-244-6543. §

Figure A
Key Symbols

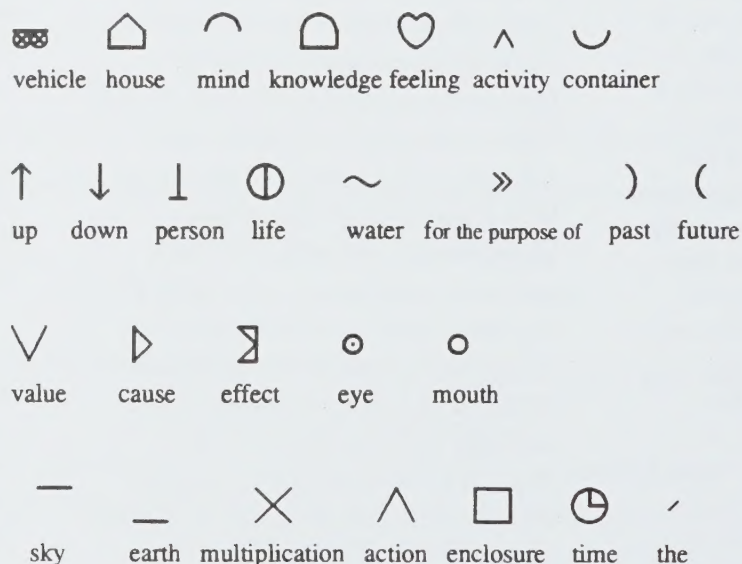


Figure B
Language Infrastructure

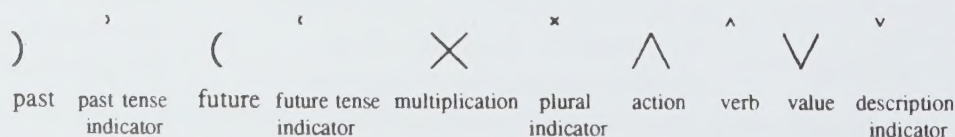
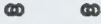


Figure C
Strategies



 combine indicator opposite meaning





 Agents of Change

Figure D
National Access Awareness Week

T H E R E







 generalization transportation housing education recreation employment

Figure E
T H E R E + C

(T'CHEER TECH'ER)








 generalization transportation housing education recreation employment communication

$\hat{I}^x \setminus \emptyset$ $\hat{I}$
Persons with a severe speech impairment need









generalization transportation housing education recreation employment communication

Persons with a severe speech impairment will give to the world

new knowledge

values ideas observations

Persons with a severe speech impairment agents (of) change

effect = better world for all persons

The International Society
for Augmentative and Alternative Communication
(ISAAC)

**Communicating Together,
and Augmentative and Alternative Communication
(AAC journal).**

ISAAC, P.O. 49 The Donway West, Suite 308,
Toronto, ON. Canada, M3C 3M9

**Please
send us
your
new address.**

Writing Letters

NOLA MILLIN



Nola Millin

So What is *Real* Communication Anyway?

I expect that everyone who is writing an article for this issue will have his or her own view of what *real communication* is, which is the reason it became the theme. As I was getting ready to write this article, I was trying to differentiate between just plain communication and *real* communication. I have come up with the following conclusion. For me, plain communication is often done out of necessity. We communicate our needs or we communicate to be sociable but this communication can be very superficial. *Real* communication happens when we truly communicate our thoughts, feelings, and ideas that lie beneath the surface. Real communication can be difficult to achieve even for people who have "normal" speech. For those of us who use an AAC device, it can be almost impossible.

I'm a woman so I have always had a need to communicate. I'm not trying to be chauvinistic by saying this but it's a known fact that women talk more than men. We express ourselves better and we use more detail. Just because I'm an AAC user, my desire to communicate hasn't changed. The methods I have to use, however, have been altered a bit. I realize it takes me longer to tell someone something than it does a person who has "normal" speech. People are so busy these days that they don't have enough time to wait until I either point out my message on my word board or type it into my voice output device. I use my word board and

Real communication can be difficult to achieve even for people who have "normal" speech. For those of us who use an AAC device, it can be almost impossible.

voice output quite effectively for day-to-day stuff and for superficial conversations. It still takes time to get my message across even though people say I'm quite fast using my devices. I find one of the worst things an individual can ask me is "What's new?" It's so broad and general that if they truly wanted an answer, it would take me five hours or more to give them a response. This certainly isn't practical for the person asking the question and it isn't practical for me. Sadly to say, I usually respond with, "Oh there's nothing much," when in reality, there's a lot going on in my life.

Typing Letters

Years ago I started typing what I called "general letters" to my friends and family. They were letters I could give to a number of people to read. The letter would inform the individual of what was happening in my life. These letters were very effective but they were a pain to write. I used a typewriter to type up the letter then I had to take the letter to the library to copy it. At times I would have to cut a certain section out before giving it to a particular person. (Like most people, I don't share everything with everyone.) Although these letters were very time consuming to do, I found they helped build good friendships. Friends actually knew what was going on in my life and could ask me specific questions when they saw me.

Getting a computer

Getting a computer really opened up my world. First, my computer eliminated the need to go and get things copied at the library. Second, I started keeping a journal. I don't write in it every day. Instead I add to it if something happens that I feel is important enough to remember and share. I use these journals to create letters to my friends and family. Obviously, I can cut and paste right on the computer or I can add and delete so letters can be personalized without much effort.

Now with e-mail, my life is even better. I can send letters and "updates" as I call them to everyone I know on e-mail. It's a fast and quite effective method for me to let people know what is happening. Here's an example of how it has helped me to write these letters. I'm very active in my church and many of my friends

from church have e-mail. Just recently, I tore a muscle in the back of my leg causing me to be even more disabled than I already am. My close friends all heard about my leg through my e-mail letters. The following Sunday one of my friends made sure she was at the door of church to meet me because she knew I might need a little more help getting around. It's a small issue, but by having written letters to these people, I saved a lot of time. They didn't come up to me and say, "What did you do to your leg?" Instead they were able to ask how it was doing or if the pain was easing up.

Letter-writing is my way of making sure that real communication will occur. I write a lot of letters. Friends tease me saying I don't write letters, I write novels. I have a few people who say whenever they receive an e-mail from me and it begins with, "Here's what's happening," they hit the print button on their computer or they wait to read it until they're off-line because they know it will be long!

I even write letters to my doctors. Those are usually just one page. My doctors appreciate them because, again, they are busy and my letters save them time. One doctor said he wished all his patients would write

letters. My letters are very explicit which enables my doctor to ask specific questions and to determine his diagnoses.

I realize letter-writing isn't for everyone but I know for me it works. It gives me the means to have real communication with people. It has allowed me to establish some close relationships and it is a way for people to get to know me. I hope, instead of just communicating everyone has a way to achieve real communication with at least one other person in his or her life. Letter-writing has been the way for me to do it.

§

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

The Official Journal

of the International Society for Augmentative and Alternative Communication

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International in scope and transdisciplinary in approach,
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Buying into *Real Communication* and the Real Person

TRACY SHEPHERD



Tracy Shepherd

What do I mean "buying into"? Let me try to explain. Let's take the example of herbal medicines. I don't really know if they work but I know some people use them and swear by them. You might say they "buy into" the benefits of using herbal remedies. Because they "buy into" the idea of why this is a good way to spend one's time and money, they will then take the time and spend the money to try to achieve the benefits that may result from using the herbs.

So how does this relate to AAC? You anti-herbalists out there are thinking, "Great, she just related something as important as communication to something as hokey as dried plants." So you see, if you don't "buy into" herbs you probably don't use them nor do you suggest to others that they should try them. What would it take for you to try the herbs? I guess, if enough people told you enough good things about them and

their benefits, you might try them. Or you might not! If you saw some of the benefits in other people, you might try them. But I venture a guess that if you tried them and had few or slow results you might not be inclined to continue. So if you weren't that committed to them and only used them half the time, I suppose the benefits would come even slower if at all. Do you see where I am headed?

A better example might be the gym and exercising. Where I work out they tell us that if we want to see results we should be going at least four times a week to make a change, three times a week just to maintain. Well, I guess after going four times for one week and not seeing any results I really didn't give it enough time to achieve the intended results. So why didn't I keep going?

Maybe in some cases, it is easier to help but the "payoff" to having children struggle is that they are learning skills that will help them be more independent.

Did I "buy into" the idea of investing that much of my time? Or did the "payoff" just not come soon enough so I decided to go out for ice cream?

Given the context so far, let's now look at what we are asking families using AAC to "buy into". The strategies and devices we want to incorporate require work and programming and training, and time and money and more time! Often, particularly when working with children, there is some time before we start to see the "payoff". Do we "buy into" something when we aren't really sure if it will work? Often the "payoff" is so far down the road, that it is difficult to keep up the work when we see no immediate gains (like at the gym).

What is the "payoff" for buying into augmentative communication?

The "pay off" is *power*! Children with disabilities are already dependent on us for so many things. Let's not feed into this by thinking that they need us to interpret their communication. They should have the experience of communicating with others without our facilitation. Give them the power to direct their own care, to decide what to wear and to talk on the telephone to their friends, by themselves. AAC can help them do these things but tremendous support is needed in the beginning stages. Clinicians can give the starting point but families and care providers have to take it from there in daily life. Families and caregivers have to provide opportunities for successful independent communication. I am not suggesting that families do not use other methods of communication that are quicker and more easily understood by familiar partners. What I am suggesting is that we need to strike a balance. Isn't it hard to watch a child with motor difficulties struggling to reach for a symbol or waiting patiently for a scanning array when we know which one she wants? Wouldn't it be easier to just help them with it? Maybe in some cases, it is easier to help. But the "payoff" to having her struggle is that the child is learning a skill that will help him or her be more independent.

So how do we get care providers to "buy into" the concept of real communication?

It takes time and trust. We just keep trying. We keep telling them the benefits of the various strategies and devices we are recommending. We give them opportunities to see other children communicating in various ways. We introduce them to other parents who have gone through or are going through the same things. We help them see even small successes.

Sometimes families and care providers tell us the right things and we feel they are "buying into" the value of the systems. But when we visit, it is quite apparent by the dust on the system that it is rarely used. No changes or additions have been made. Communication is dynamic. Thus communication systems should be dynamic as well. It is often quite clear if a child has had the opportunities to explore communication

What happens if they don't "buy in"?

Quite frankly, nothing! It is the responsibility of care providers to demonstrate and provide opportunities for individuals to learn and use alternative forms of communication when their speech is not functional. One might hear "but I understand everything they are saying." In many cases that is the truth. Those who are closest to individuals with dysarthric speech do understand much of their speech, *but* the general public does not!

Let's take Nola Millin, one of the associate editors of this magazine, as an example. I know that many people who know her quite well can understand a good deal of her speech. I am one of those people (if I have my head on straight that day). Even so, Nola needs a back up system to communicate with those who have more difficulty understanding her speech. Most individuals who learn to use an augmentative form of communication don't do it overnight. Time and practice is required to learn and become proficient at using these systems (Nola, by the way, was a bit of an exception to this. She learned to use her current voice output system in about 20 minutes). So, for children learning language and literacy, we need to work together with their parents or caregivers to incorporate all those emerging skills within a communication system. I am not saying it is easy. I am saying it is essential in order for them to grow up to be effective, independent communicators.

Why don't care providers "buy in"?

I hate to always be so negative but I

feel the need to paint a picture. In my heart, I would like to feel that I am making a difference in the lives I touch on a daily basis. Sometimes I do. More often however, I think I am fighting battles that nobody can ever win, especially the child. Families are in varying stages of accepting their children's strengths as well as weaknesses. Families also can't do it all at once. They may not even see communication as being the most important thing right now. I can't impose my views about communication on a family who might be more interested in the child learning to take his or her first steps. What an excellent goal to be pursuing!

And what about speech? How can we think of introducing a device or symbol system to a child at the age of four? To a parent, this inevitably means we are giving up on speech. This is quite a barrier to cross in order to begin the work on augmentative or alternative forms of communication. We need to help them see the value in providing children many opportunities to communicate in many different ways. Sure, sometimes it will be easier for the parents to guess what their children want because they know them so well. But time has to be built in to let children learn what it is like to communicate on their own without intervention or facilitation from mom and dad or the educational assistants. If we keep doing it for them, how will they learn to do it themselves? Remember the "payoff" is *power*.

Who else has to buy in?

Communication partners must also "buy in" not only to communication but to the real person. So many times I have found myself with a child in a community situation where the community partner just does not know how to respond to a person using a computer voice or a person who communicates in a way that is different. Our communities need to be educated. What a daunting task! I know that with **Communicating Together** readers, I am preaching to the

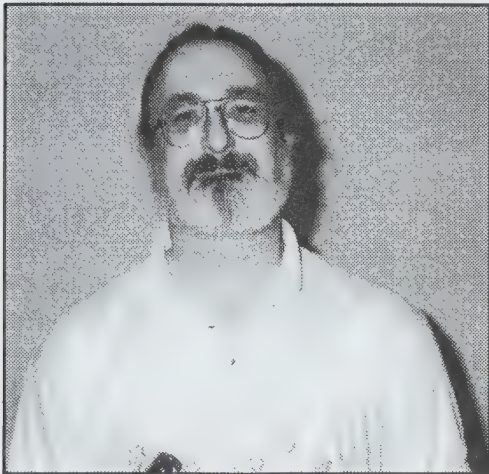
converted. Even so, the point has to be made that much of the general public is left with their mouths agape when an AAC user approaches, let alone orders food at McDonald's.

It reminds me of a patient in one of the episodes of ER, a popular American television show. Okay, you all might not be ER junkies like myself, but it is relevant. A patient with cerebral palsy enters the emergency room. He has been hit by a car and is bruised and bloody. The man has pretty dysarthric speech, but is fairly intelligible and obviously trying to communicate. The doctors keep asking him questions. But they do not wait for answers and are not attentive to his attempts to communicate. The man is alone and the two doctors are talking over him on the hospital bed about finding out who he is or where he lives. He starts banging on the hospital bed with his leg. He repeatedly bangs on the bed to try to get their attention. The doctors think he is having a seizure! Anyway, they do a really good job of showing what the general public (doctors included) tend to do when faced with an individual they don't understand. It turns out this man began to bang out the numbers of his phone number. The doctors finally "got it" and called the number. Of course this guy was brilliant and spoke about four different languages. He just wasn't given the chance. I know this example is taken from a fictional show but I think a good deal more of this awareness for the general public is needed. And let's face it, a large number of people watch ER.

Let me close by saying families and care providers have to "buy into" the worth and power of communication. That message has to be sent to the people their children interact with on a daily basis in order that real communication with AAC users can be observed by the general public. Society must see them as real people with something to say. Wow. It is a big order to fill but I'll do my part! §

New Things Coming for ComTog Online

ROBERT HAAF



Rob Haaf

Hello everyone. Actually, at this point I'm always tempted to say Happy New Year, since this is usually the first issue to come out after our annual associate editors' meeting, where we set the themes and content for the next four issues. As usual, we all came away from the annual meeting with new ideas, insights and motivation (not to mention more work!) I would like to take a moment in this issue to talk about one of the results of our efforts, in regard to the focus of the *Getting Technical* column over the next year and how this fits with the **ComTog Online** web site and electronic magazine. Some of you may be surprised to find that I intend to take a largely positive and encouraging stance on some developing technologies! Personally, I'm pleased to be able to do just that (for a change).

Among many other topics tackled during our annual meeting, there was repeated discussion about the internet, and the form that **ComTog Online** can and should take within the expanding online world. Specifically, we asked ourselves these questions: How can we best encourage **Communicating Together** readers who are not yet online to explore some of the distinct advantages that this technology can offer, and how can we increase the "value added" features of the **ComTog** web site and the electronic version of the magazine? While opinions around the strengths, weaknesses and long-term applications of the internet will continue to vary drastically for the foreseeable future, we agreed that:

A headlong rush to bring everything and everyone online wouldn't be a prudent course. The reason for this is an obvious one. Despite the hype and hoopla surrounding the internet these days, currently only a small percentage of people in general are online, and we have to assume that this applies to our readership. Before we can comfortably continue to expand our online offerings, we should first take the time to provide a range of necessary information, focusing on the uses and advantages of the internet for communication professionals, AAC users and their families. We also have to lead our readership online by providing them (you) with a motivation to explore and discover this burgeoning information and communication medium. Given the sometimes overwhelming amount of information and resources available, we must provide a focused entry to the internet via discussions

of the available resources related to AAC.

So, if we want to encourage readers to explore the potential benefits of being online, then we can start by increasing the benefits that we offer through our own online presence. If we can give you some compelling options for gathering information and resources relevant to communication and AAC, and in doing so tweak your interest in this medium, then who knows? One day we may find you all clamoring for **Communicating Together** to move online completely!

(Yes, I know that this doesn't apply to you avid web surfers out there. Please keep in mind, though, that we represent only about 20% of the population, and by extension 20% or so of those who read **Communicating Together**. For you, we hope that the information and options we're developing will prove to be of use as a source and starting point for gathering information on AAC, assistive technology and the internet, and that you will have a reason to visit and use our web site.)

To further these ends, over the next few issues the *Getting Technical* column will present a series of articles focusing on the internet. We will begin next issue with an overview of the main features of the internet, common terminology, hardware and software, etc. This article will be aimed at "internet neophytes", and will provide the basic foundation needed to get set up and begin using the net for your own purposes. This will be followed by an article focusing on access to the internet by individuals with disabili-

ties, including what tools are available to make web surfing and writing e-mail more efficient and what features should be incorporated into web sites (and browsers) to make them maximally accessible. Finally, I want to discuss one view of the future of the internet, what forms this infant medium might take, and what this technology will likely offer individuals with disabilities and their care providers in terms of information, support and most importantly the ability to communicate and interact on a more level playing field than ever before.

The articles in the print magazine will (we hope) provide readers with a core of valuable information about the internet, from a perspective that will be relevant to communication professionals, AAC users and their families. In addition, we want those of you who access the electronic version of the magazine to be able to better experience the interactive aspects of electronic publishing. One of the benefits offered through the electronic version of **Communicating Together** is the ability to link information in the articles directly to other informational sites on the web, to specific files and programs to download, or even to specific individuals via e-mail. So, if you're reading the electronic version of **Communicating Together** and a particular reference interests you, you can gather detailed information, download the file being discussed or fire off a message to the author with a single mouse click. These features are all readily available today, and will be available to you starting with the next electronic issue.

In addition to providing a series of "internet-focused" articles in the magazine, it was agreed that **ComTog Online** should also begin to offer more opportunities for its

readership to communicate with authors and editors and to contribute to discussions and debates that will only begin in the printed magazine. One of the most liberating features of the internet is the opportunity it provides for everyone to become a participant in group discussions and to contribute to the content of a publication. We decided during our editorial meeting to try to implement this kind of interaction on the **ComTog Web site**, and ultimately back into the printed magazine itself. Starting with an article to be selected from this issue, anyone who accesses the **ComTog Online** site will find a web-based "message board" focusing on a particularly compelling (or controversial) article. Any reader will be able to read the ongoing discussion, post their own message(s), comment on the story, start a dialog on the issues with other readers, share his or her opinions with the author(s) of the article, or all of the above! In addition to the discussion board on the web, if we can get a dynamic, interactive discussion going, we will publish highlights of the commentary in the following issue as a printed response to the original story. We hope that

this will not only provide writers and editors with valuable reader feedback on their articles, but that it will also result in a richer, interactive and more complete discussion of the topics and issues that we raise in the magazine.

I can't (and won't) speak for anyone else, but I for one am excited at the potential offered by these changes. The majority of my work time these days in fact is spent developing for the web or teaching others about new media. I communicate with friends and colleagues through a couple of e-mail accounts, and so on ad nauseum. I'm as wired as they come, I think, and believe strongly that despite the clamour and clutter we see today, this medium will become as indispensable as all of the revolutionary rhetoric keeps promising, and will soon expand into many aspects of our lives. Knowing my biases ahead of time, I hope that, given the previous articles on technology and its impact on AAC that you've seen published in **Communicating Together**, you will still be confident that our approach to this issue will be a balanced and critical one. See you all on the web.

§

New Rates for Communicating Together

(starting with the Spring issue, 1999)

	ISAAC Members	Non-ISAAC members
Canadian	30.00 Cdn	35.00
US	28.00 US	33.00
International	34.00 Cdn	40.00

Rates for consumers, students, seniors

Canadian	25.00 Cdn
US	23.00 Cdn
International	30.00 Cdn

For **ComTog Online**, add \$5.00 to above rates.

Communicating

ALDA STEPRANS



Audrey McGee

I remember when I first met Audrey, a year or so after she had had a major stroke that took away her speech. What an unhappy, frustrated soul she was. But over the course of her first year living with us she changed enormously and is for the most part, a very content great-grandmother, taking joy in all the people around her. We all gain a lot from her and her attempts to continue learning and teaching us.

Here is what Audrey has to say about communicating.

I get to communicate most of what I want to say. My spelling is bad, though. I used to be a great speller. Now I just can't get the right letters to come out, especially when I'm tired.

My little voice synthesizer, my *Lightwriter*, helps me to communicate. I had a trial with it and it

worked so well that I kept it. Even before I had it, I could communicate well using my letter board, at least with those people who took the time to communicate. I'm persistent. I don't give up if I have something to say. Even if my spelling is wrong, I try again. The *Lightwriter* helps me communicate things I cannot say any other way.

Sometimes when I can't spell I get extremely frustrated, but people figure out what I have to say most of the time. My facial expressions help them, too.

Sometimes when I can't spell I get extremely frustrated, but people figure out what I have to say most of the time. My facial expressions help them, too.

Some people, who don't know me, think I can't communicate. It takes patience for people to understand me and people are often in a rush. Some nurses don't take the time. My family is very good. They generally take the time to understand what I am telling them.

I feel I communicate well and have good relationships with the staff in the hospital I live in. I don't communicate as well with the other residents. I often can't hear what they're saying — many have very soft voices, or I can't understand their speech. I spend a lot of time with Steven Hanlon, who also writes for this magazine. We often play

dominoes and cards together. But I don't understand most of what he says. It makes me feel that I am impatient. I do try though, and it makes me feel very good when I do understand him. Most of the residents here don't communicate well. My room-mate has trouble with her vision and her hearing. She cannot see the words I am trying to spell. Although I can't communicate with many of my neighbors I still feel I know them as people, just from seeing them so often, watching their faces and movements.

Speech therapy has helped me a lot. Nicole, the therapist, has made up a communication board just for me. It contains all the everyday, usual things I need to communicate quickly.

I haven't given up trying to talk. One side of my tongue is paralyzed, so it's hard to control it. Sometimes when I say things, people understand.

I also communicate through my painting. Painting is a new hobby for me, one I started in the hospital. I paint cards for weddings and birthdays, to let people know how much I care about them. I'm paralyzed on my right side, so have to use my left hand to paint — it's not easy and takes a lot of work!

§

Barriers to *Real Communication*

GEB VERBURG



Geb Verburg

I trust that *Real Communication* will be (a) understood by the readers in the way that it is meant in this issue; (b) defined elsewhere in this issue; and (c) explored a bit further in this article; but really (d) all of the above.

The need for an issue dedicated to real communication is based on the perception of the editors that what is happening in AAC, while obviously communication, is perhaps not enough like *real* communication. I am not sure how many professionals working in AAC would agree with that sentiment. I would say that the more that do so, the more mature the field of AAC has become. After all, it is not easy to dedicate one's life to fostering communication of non-speaking persons and to have to say that, after all this time, we still have not yet fully succeeded. I invite you to take that perspective for a little while.

We can say on the one hand that we have come very far. Previous issues of **Communicating Together** have made that point. But we must go on to say that we still have a long way to go for our clients to partake regularly in *real* communication. Maybe if we take this perspective — that something is still missing from the communication process and the devices and tools that are at our disposal now — then maybe we can learn something that can help AAC clients.

What Distinguishes “Communication” from “*Real Communication*”?

Communication with AAC involves the system, its processes, and the persons in the AAC user's environment that afford or allow them to “communicate”. This is to be contrasted with a communication situation where the communication partners, assistants, teachers, co-workers and strangers actually do communicate with an AAC user just as they would communicate with people who speak. What is the difference in these two situations? I think it relates to four primary factors (1) to time, (2) to attitude towards disability, (3) to a lack of education or experience, and finally (4) to technology. Although I'm afraid it is not possible to actually tease them apart in real life, let me discuss each of these briefly and separately.

Time

Time is the first and the most easily blamed cause of why people do not communicate as fully, as extensively, and as easily with people who use an AAC device. After all it takes from 75% up to

three times longer for an AAC user to communicate a simple intention or observation as it does for a speaking person to communicate the same intention or observation. People are simply not used to taking the time necessary for real communication with AAC.

Attitudes towards disability

I have chosen *attitude towards disability* as the second cause of the lack of real communication. Too many new people one meets daily, as well as a large portion of the ones we meet regularly, are not comfortable interacting with people with disabilities. This in itself puts a strain on the conversation over and above the strain already resulting from the extra time that must be taken to communicate with an AAC user. Moreover, these two factors of time and disability probably have some kind of multiplicative effect on the new, or potential (or never to be) communication partner.

Lack of experience and training

My third candidate for a major factor that contributes to the degradation of the real communicative exchanges between people with and without communication devices is the *lack of experience, training or education* of the persons who do not use an alternative communication device (i.e. the people who use their voices). It is depressing. The bulk of people that an AAC user might want to talk to lack the special training or experience they need to interact comfortably with someone who uses AAC devices. In most cases, they simply have never had an opportunity to learn. Perhaps this will be remedied in the future. There is a

new training video now available that I want to talk about shortly that may go some ways to remedy these problems. Let me discuss first however my last obstacle to real communication — *technology*.

Technology

The AAC *technology* itself is more than a bit daunting or strange. I personally find the simple alphabet boards the most comfortable to deal with. Certainly, they are far less threatening to deal with than the black boxes that often display poorly illuminated, hard to read bits of text or which produce sounds that are often even harder to understand. Every device looks different, works differently, and comes without even the briefest of introductions to help put new potential communicators at ease or to tune their listening. Why can't these devices have a simple little message that says or prints as slowly and clearly as necessary, something like:

Hi, my name is NN. I use an XX voice replacement communication device. I am very slow so please be patient with me. Can you understand me at this speed and volume?

This kind of introductory message would provide an instant opener and icebreaker. Rather than pretending that the technology is not there and attempting to enter immediately into a conversation without any preliminaries, it acknowledges the unusual technology and places its oddity right up front. The user must of course have the option to skip the blurb, but even with familiar people, it would help me to hear an introduction so that I can remember how to listen to this particular person's machine. Instead of the personal blurb, you might have a company promo, or play a joke, so that listeners can tune into the particular voice properties of the specific machine

they will be listening to. Whatever the material chosen, some sort of introductory message designed to put the person at ease and helping him or her to adjust to the unusual communication situation is important.

There are obviously more things that interfere with real communication, such as lack of experience or lack of confidence on the part of the AAC user. These four however allow us the opportunity to consider two important questions.

Questions and Answers

1. Can we do anything about time, attitudes towards disability, experience and technology — the four negative factors that can interfere with real communication?

Time is a difficult one. I know many people have worked on this. Aside from developing more powerful hardware or more sophisticated abbreviation or conversation substitution-type software, this is not an easy problem to solve. The time delays are in most cases caused by extremely slow access speeds which are (still) typical of people with significant physical impairments.

Attitudes towards disability and experience with AAC users: Long-time readers of this column know that I am very pessimistic about changing people's attitudes about disability. I share the hope that integrated schooling and integrated community living may eventually help children (and adults) develop a level of comfort and familiarity with peers with disabilities that may make a big difference in the longer term. I believe that the only way for attitudes to really change for the better however is to have close (enough) contact between people with and without disabilities.

There may be help on the way in this area however. Barbara Collier together with a number of her colleagues and friends has put

together a video called *Communicating Matters* (1998). The video is intended to train attendants and other people who work with or for people who use AAC devices. It is 47 minutes long and is produced by William Bobek Productions. The tape is meant for attendants and people who are new to communicating with people with AAC devices. Designed as a teaching video, it contains a number of typical communication scenarios where errors are demonstrated, analysed and discussed. After each scenario the tape suggests that the learners stop the video and discuss the implications of the communication exchange.

Technology: I almost feel that I have said enough negative things about technology. More significantly, most of my AAC technology experience is based on the boxes that I see on the chairs of friends and clients that I meet and with whom I communicate. Most of these boxes are old, bordering on ancient. I am thus not familiar with the newest and hottest technologies and do not know if they have solved the problems that I so cavalierly attributed to them. If they have, I apologize and hope that all my friends are soon due for new communication equipment.

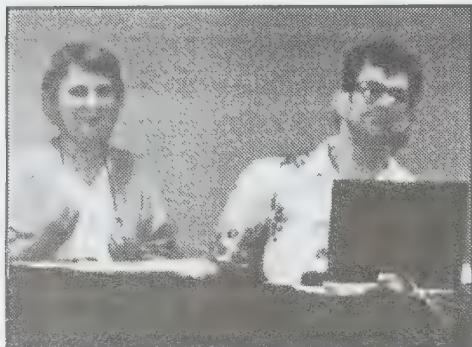
2. Are there situations or environments in which the four factors of time, disability/attitude, experience, and technology do not play a role or at least do not play a negative role?

Yes, there are situations in which some or all of the negative conditions could be considered positive ones. Watch for the next *Contexts!*

Communicating Matters is available from: Harmony Place Support Services, 132 Railside Rd. Unit 6, North York, ON Canada M3A 1A3. \$135.00 Cdn. (tax included)
fax 416-510-0824

Learning Through Metaphors

PAUL MARSHALL &
SHIRLEY McNAUGHTON



Shirley McNaughton and Paul Marshall

*In this edition of Paul's Place, Shirley McNaughton and I share the experiences we had at the recent CASHRA Conference we attended in Halifax this June. The theme of the conference was **Agents of Change**. It was a very moving and enlightening opportunity for both of us. Here we try to capture what each of us learned that is relevant to AAC.*

From Paul: Opening Up Our Windows

As you have already learned from the *Feature* article in this issue, Shirley McNaughton and I attended the Canadian Association of Statutory Human Rights Agencies (CASHRA '98' Conference) in early June. We were both surprised at how at home we felt among the participants and we both were profoundly affected by the experience. It was a good feeling to be with a group that was so highly motivated and concerned with every aspect of human rights, including

the right to communication. Both of us came away with many new ideas and with a knowledge that there are untapped resources which can benefit many people.

The conference focused on the big picture, on what the next millennium will look like. The topics discussed ranged from the rights of nations, to globalization, to the rights of the individual. After interacting with the conference participants, we felt there was a great need to bring many issues concerning the AAC community to groups like this, in which there are persons working to improve the rights and quality of life of all vulnerable people. The underlying theme addressed in the conference was:

How can we, as human beings heading for the 21st century, reach out to our neighbours and be a force for positive change?

One of the many remarks that impressed me came from Mme Ndèye Fall. As she ended her presentation, she noted that as human beings, we need always to be reaching for the place where the 'they's' become 'we's' and the 'you's' becomes 'me's'. What a powerful thought. Think how it would impact on our lives if we actually lived according to that rule. It is human nature to try to protect ourselves and obtain the highest lifestyle possible for ourselves. What would happen if we truly wanted to provide the same to others? Would we end up struggling to keep ourselves above water? Or would we die and finally experience the place where the 'they's' truly become *us*?

Another idea that greatly impressed me came from Peter Gzowski, the keynote speaker for the conference. In his address, Mr.

Gzowski wondered what would happen if we didn't get our newspapers and just turned off our televisions and our radios. Would we be able to see, to hear, to understand the world for ourselves? Would we open up our windows so that we could experience the world first-hand without someone else interpreting it for us?

As I am writing this article, my window is open and I can hear children playing. This is our future generation, the one that will design my old age home. The society in which they are growing up comes with many negatives. Are we to be a closed window society with our TVs and radios turned up so that we block out the things that really matter? Or can we open our windows and hear and see what is happening around us?

When I look at our theme of *real communication* for this issue of **Communicating Together**, I question why we need the word *real*. Why don't we just say communication? For the past while, I have been listening for how many times I hear the word *real* in daily conversations. Is the world so fake that we need to use the word 'real' to get across the point that the subject that we are discussing is truly important? If this is so, I say open up your real windows.

Communication starts by hearing the needs around you and acting upon them. The lesson of the conference for me is that simply to buy into the latest modern thinking and react blindly to circumstances as I have always reacted is not the most beneficial thing for me to do today. Is it for you?

From Shirley: Dismantling the Outposts of Our Minds

From start to finish, the Canadian Association of Statutory Human Rights Agencies, CASHRA '98' Conference on "Change Agents for the 21st Century" provided a feast of exciting ideas. It began with a Sweet Grass Ceremony conducted by Maxine Knockwood, traditional Mi'kmaq Elder. The conference sessions covered such diverse topics as alternative dispute resolution, systemic discrimination, discrimination from an aboriginal perspective, discrimination based on multiple grounds, globalization, human rights in the corporate structure, children's rights, systemic discrimination in employment and education through biased psychological and standardized testing, women and the global economy, and disability and integration in education. The final day featured Sheree Fitch, a children's rights advocate and children's author as the luncheon speaker. At the closing plenary session, the singing of Terry Kelly, East Coast Music Award winner, accompanied his comments relating to his own blindness.

I am so glad that Paul Marshall asked me to share in his presentation. He had been invited to speak on augmentative and alternative communication (AAC) and to consider AAC as a *Change Agent* toward human rights in the next century. Neither Paul nor I knew anything about CASHRA or its members. We both however looked forward to the opportunity of meeting persons who were activists in the area of human rights. We were not disappointed! We also welcomed the opportunity to share our thoughts regarding AAC users, human rights, and the work we are doing to

support BlissInternet as a powerful change agent for the 21st century.

The highlights of the conference, for me, began immediately with the warm opening remarks of Mary MacLennan, CASHRA President, and Chairperson, Nova Scotia Human Rights Commission. Ms. MacLennan had made every effort to greet individually those of the 200 conference participants who attended the reception the previous evening. Her welcoming remarks were just as inclusionary as the conference program itself. It was wonderful to observe, as she spoke, her skilful and unobtrusive arranging of her notes on a low table, and the adjustment of the microphone — with her foot. As Ms. MacLennan nonchalantly compensated for her lack of arms, I knew this was truly going to be a gathering where being different was OK!

This is not to say that there were not moments when Paul and I felt his lack of speech and his use of an alphabet board presented a barrier. It was evident that few conference attendants had had any experience with augmentative communication. We were reassured, however, by our knowledge that many of those present were trying their best to overcome their initial lack of ease. Paul and his mother, Rosemary, went a long way toward changing attitudes during the three conference days.

The keynote address was given by Peter Gzowski, author and former host of the Canadian Broadcasting Corporation's *Morningside*, a program that was cherished by a large band of listeners across Canada (including this writer). Mr. Gzowski expressed his concern regarding the rise of corporatism and the shifting centre of gravity in Canada as the public sector is "reduced, opposed and/or dismissed" and as business

exerts more influence on the arts, sports, universities, etc. He urged human rights agencies to work together and speak out to push the pendulum back toward "the mutually supporting country we once knew". For we newcomers to CASHRA from the AAC community, Mr. Gzowski's remarks provided a very comfortable introduction!

Following the keynote address, the plenary session continued with a presentation by Dr. Frank Blye, Associate Professor of Education, Mount Saint Vincent University, Halifax. As he discussed "*Systemic Discrimination and Education*", he drew attention to the everyday social practices that reinforce discrimination and he gave examples of sexist ideology masked in the attitudes and beliefs of many educators regarding children from single parent families and those lacking male role models. He urged us to examine and try to understand the historical and emotional contexts of many of our beliefs.

While Dr. Blye's examples related primarily to racial and sex discrimination, my mind flew to the historical influences that "saturate our bodies on a daily basis" as we who can speak interact with AAC users. I was reminded of a colleague's remark recently, upon reading the March, 1998 issue of **Communicating Together**. She commented on how shocked she was to realize that she had been considering the AAC adults with whom she had been working for many years as almost asexual. She wondered how she could have been so blind or so insensitive. Yes, the historical roots of our attitudes do indeed run deep.

Dr. Blye challenged us to "speak and write ourselves into the future in a different way". The metaphor he provided will stay with me for a long

time. He identified the need to "dismantle the outposts in our heads" and urged the use of a systemic approach to "write others into the social text by accepting and fostering difference". We do indeed need to open our minds to the new and the different when they represent advances in human abilities. As an AAC participant throughout the past three decades, however, I realize well that dismantling well-established "outposts in the mind" will not come easily!

The second day began with a legal update from William Pentney, General Counsel for the Canadian Human Rights Commission and a UNESCO update by Mme Ndèye Fall, UNESCO Representative to Canada. As Mme Fall began her address, she commented that she would not use her written script. She preferred to extemporize, as the "talking word has life". An interesting observation viewed (as I always tend to do) from an AAC perspective. As well, it was a challenging half-hour for the translators!

The '98 CASHRA Conference provided an excellent opportunity to reflect upon the progress and the disappointments in the fifty years since the Universal Declaration of Human Rights on December 10, 1948. The UN General Assembly adopted this declaration without a dissenting vote, and the conference endeavoured to use the learning that has been achieved since then as the context for charting the direction for the next millennium.

The most memorable presentation (for me) was given by Maude Barlow, Volunteer National Chairperson of *The Council of Canadians*. Her topic was globalization and the threat it presents to human rights. She described the move toward privatization of government services taking place in Canada, the world-

wide transcending of nation state political powers by trans-national corporations, and the creation of global institutions to promote the interests of trans-national corporations. She summarized her thinking about the Multilateral Agreement on Investment (MAI), the concerns of which have been captured in her most recent book, coauthored with Tony Clarke (1997). The implications of the MAI for human rights were identified by Ms. Barlow as (a) low standards for labour working conditions, (b) more free trade zones in which national rules regarding environment and human rights would not apply, (c) dispute resolutions through binding arbitration by international bureaucrats, (d) the imposition of most favoured nation status and the concomitant removal of restrictions on foreign investment, and (e) the use of countries' security forces to protect the interests of multinational companies against countries' own citizens. She reported the availability from the Council of Canadians of a proposed "Citizens' MAI", designed to protect citizens, in which obligations toward the countries in which they have investments are placed upon transnationals.

I was left with another vivid metaphor which Paul began using within hours of her address. (It's an excellent metaphor for Paul to gesture!) Maude Barlow described the current efforts of human rights organizations as valiant attempts to bale out a boat with numerous persons frantically emptying baling containers. All the while, multinational corporations are sawing off the back of the boat! It's a haunting maritime image!

At the closing day luncheon, Sheree Fitch read from several of her books for children. She left me committed to searching for "*If You Could Wear My Sneakers*" the next

time I visit our book store.

Following lunch, it was time for Paul and me to prepare the room for our multimedia presentation, as one of the final workshops of the conference. We had wonderful help from the audio visual staff (especially Derrin) and a supportive moderator, Charlach Mackintosh, Chief Commissioner, Alberta Human Rights and Citizenship Commission. He made sure that we had the complete time allotted even though the room was booked immediately following our session for another session, and our start was delayed due to previous sessions running overtime. The written version of Paul's presentation is the *Feature* of this issue and my presentation appears in *SymbolTalk*.

Before closing, I want to share the link I discovered between the goals that I hold within the AAC community and those of the human rights activists I had the pleasure of meeting in Halifax. The connection relates directly to the theme of this issue of **Communicating Together** — *Real Communication*. It can only flourish when individuals around the world eliminate those guarded outposts in human minds that prevent new and different ideas from entering. Unobstructed and genuine exchanges of individuals' ideas and feelings and intentions constitute real communication. At a person-to-person level, the attitudes and values of AAC users and their partners need to be those of acceptance and patience. After twenty-five years in an AAC environment, I still see far too many examples of AAC users being manipulated or forced into following the agendas of their caregivers, their service providers, their government and their non-profit service agencies. Real communication can only exist when the ideas of each AAC user can be freely ex-

pressed and when the necessary time is given to ensure that the messages are listened to and that responses are given. At the organization level, collaboration and the shared undertakings between similar-minded agencies have to be established and vigilantly maintained. Here, the mental outposts of the mind that fear competition for resources and resist unknown allies need to be eliminated.

The CASHRA Conference of 1998 gave me a glimpse of what could be possible in the next millennium. It requires the united efforts of many diverse groups to combat inequality and injustice toward individuals in all parts of the world. I was proud to co-present with Paul Marshall the contribution that we, along with Peter Lindsay and our Blissymbolics Communication International colleagues, are able to make. BlissInternet is our agent of change. It enables Bliss users and Bliss alumni, within an international communication environment, to achieve their human right of free expression of their ideas prior to their acquisition of literacy. It offers them support in their progress toward literacy (more on this in *SymbolTalk* in the September issue of **Communicating Together**). To those who have been given the gift of speech and who interact with Bliss users, BlissInternet gives a language that can be used around the

world. Maxine Knockwood, during the Sweet Grass Ceremony of the CASHRA'98 Conference described language as "created to help us love one another and to honour one another, and providing the means of creating an intentional shift in human consciousness". She urged us to use our intelligence to dissect intolerance. Blissymbol users can make a unique contribution to this endeavour through sharing with the world both their meaning-based international language and their insights as AAC users.

As I look back on the conference, a travel metaphor must be added to those of the outpost and the boat. Human rights organizations recognize that there is a long road ahead. They provided the CASHRA'98 Conference as supportive preparation for the journey. The three days taught me that there are many routes to travel for those who share common goals. The paths are separate but they follow the same general direction. From time to time they merge together, enabling the travelers to gain encouragement and direction from each other. As we make the journey, our challenge is to (a) demonstrate what is possible and increase our efforts in providing freedom, dignity, and equality in human rights, (b) keep baling out the boat when funding is cut and needed services are withdrawn, (c) ward off those strong globalization forces in

the rear that are continuously sharpening their saws and already beginning their work of removing the planks from the human rights' boat and (d) be vigilant in dismantling the outposts in the minds of those along the way, whose particular history and limited knowledge make it difficult for them to accept and include those who are different. All AAC users can make a valuable contribution by sharing the rich experiences they gain through communicating in a different way. Bliss users have a special gift to give — their knowledge, gained from years of experience in using their international language.

Paul and I were very aware of the many AAC users we were representing as we interacted with conference participants and made our presentation at the CASHRA '98 Conference. We felt privileged to be given the opportunity to portray their needs and their strengths to this audience that was new to AAC. The words of "Kari's song" that we played at the end of our formal presentation summarized the message we hope we were able to leave with everyone.

Reference

Clarke, T. & Barlow, M. (1997). *The Multilateral Agreement on Investment (MAI) and the threat to Canadian Sovereignty*. Toronto: § Stoddart Pub.

TAKE THE TIME

Take the time to look at me
Take the time to listen
Take the time to know me
Take the time to care
Take the time to ask some questions
Take the time for answers
Take the time to understand
Take the time to be a friend

Accept me the way I am
No one is perfect not even you
Don't think about our problems
Think about what we can do
You accept me
And I'll accept you.

Lyrics by Kari Harrington

Music by Nancy Gibbons

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Paul Marshall and his mother interacting with conference participants at the CASHRA conference, Halifax, Nova Scotia, June, 1998.

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